



**New Jersey Department of Health and Senior Services
Governor's Council for Medical Research and Treatment of Autism
Meeting Minutes – September 12, 2011 (ratified)
6pm – 9pm**

**Location: NJ Department of Health and Senior Services, Health & Agriculture Building,
369 South Warren Street, Trenton, NJ 08625-0360**

Council Members Present

Elizabeth K. Bell, BS, volunteer and independent contractor with Autism Speaks,
Autism Organization Representative

Matthew Cortland, BA, Instructor, Teach for America, Public Member

Caroline Eggerding, MD, Vice President Clinical Services, Bancroft NeuroHealth,
Healthcare Organization Representative and Chair of Governor's Council for Medical Research
and Treatment of Autism

Susan P. Evans, EdD, Education Program Specialist for Early Intervention Program,
Commissioner of Health and Senior Services Appointee

Linda S. Meyer, EdD, MPA, BCBA-D Executive Director of Autism New Jersey, Autism
Organization Representative

Barbara Morvay, MA, Trustee, Richard Stockton College of New Jersey, Academic Institution
Representative

Grace M. Reilly, RN, MSN, APN-C, Adult Nurse Practitioner for Riverview Medical Center,
Individual with Autism or Family Member Representative

Kendell R. Sprott, MD, JD, Acting Director of Pediatrics, University of Medicine and Dentistry-
New Jersey Medical School, Academic Institution Representative

Gary Weitzen, BA, Executive Director, Parents of Autistic Children (POAC) Autism Services,
Organization Representative

Barbie Zimmerman-Bier, MD, Appointment at Rutgers University, clinician at St. Peter's
University, Academic Institution Representative

Absent

B. Madeleine Goldfarb, MA, Founder/Director of the Noah's Ark Children's Association,
Autism Organization Representative

Ketan Kansagra, MD, FAAP, Children's Hospital of New Jersey at Newark Beth Israel Medical
Center, Academic Institution Recommendation

Judah Zeigler, Senate President Appointee

NJ Department of Health and Senior Services (DHSS) Attendees

Martin T. Zanna MD, MPH
Acting Executive Director
Governor's Council for Medical Research and Treatment of Autism

Cynthia Kirchner, MPH
Director, Quality Improvement
Ethics Liaison for the DHSS

Linda N. Bocclair, M.Ed., MBA
Executive Assistant
Governor's Council for Medical Research and Treatment of Autism

Mary Ray, Contract Administrator 2
Governor's Council for Medical Research and Treatment of Autism
Commission on Brain Injury Research
Commission on Spinal Cord Research

General Public Attendees

Audrey Mars, MD
Medical Director, Regional Autism Center at Hunterdon Medical Center

Susan Freedman, Regional Autism Center at Hunterdon Medical Center

Yvette Janvier, MD
Medical Director, Children's Specialized Hospital

Pnina Mintz, Ph.D.
Center for Neurological and Neurodevelopmental Health (CNNH)

Mark Mintz, MD
Center for Neurological and Neurodevelopmental Health (CNNH)

Denise Aloisio, MD
Medical Director
Jersey Shore University Medical center

Walter Zahorodny, Ph.D.
UMDNJ New Jersey Medical School

I. Welcome - Council Chair, Dr. Caroline Eggerding called the meeting to order at 6:10 PM and welcomed everyone.

II. Public Meetings Act Announcement- Dr. Eggerding read the Public Meetings Act, followed by roll call. Members introduced themselves for the benefit of the three new members. The three new members introduced themselves.

III. Approval of the June 20, 2011 Council Meeting Minutes

Dr. Eggerding called for a motion to approve the minutes. MOTION by Dr. Meyer to approve the minutes was seconded by Ms. Bell.

MOTION to approve the minutes with one correction (Public member Carole Deitchman, Caldwell College not Morrisville Hospital) was passed with all in favor.

IV. Approval of the 2012 Council Meeting Calendar

Dr. Eggerding called for a motion to approve the calendar. MOTION by Dr. Sprott to approve the calendar was seconded by Ms. Bell.

Note: 2012 Meeting dates are March 5, June 4, September 10, December 3.

MOTION passed as presented with all in favor.

V. Approval for funding for the FY 12 research grants

Dr. Eggerding commented that it is important that the research grants be approved for continuation funding for 2011-2012 to enable continuation of the work. The intent is not to diminish Council's concern over the progress made by any individual grantee but rather to be respectful of options other than yes or no votes to approve a grant for continuation funding. One option is to conditionally approve funding while requesting information from the principal investigators in response to concerns raised by reviewers.

Individual research grants:

(1) Motion made by Dr. Sprott to approve year two funding (\$197,340) for grant number 10-399, PI - G. Miller Jonakait, Ph.D., NJIT, *Mediators of Maternal Inflammation*, seconded by Dr. Evans.

Discussion regarding budget request: Not all grantees followed the budget format and requested amount for this grant was not consistent with amount initially approved by Council. Leaderboard amounts are the ones that Council is being asked to fund. The amounts are for the second year and are the same that were initially approved by Council when the grants were awarded. Moving forward, standard formats will be required.

MOTION passed as presented with yes (8) and abstentions (1).

Note: Dr. Barbie Zimmerman-Bier entered the meeting.

(2) Motion made by Dr. Sprott to approve year two funding (\$234,775) for grant number 10-400-SCH-E-0 PI- Yvette Janvier, M.D, Children's Specialized Hospital, *Autism outreach/screening in under-served area*, seconded by Dr. Evans.

Discussion followed regarding providing reviewer's comments to principal investigators and the process to ensure that concerns are addressed. When Council approves funding the principal investigator will receive a copy of both the primary and secondary blinded review. Council can request quarterly progress reports, clarification of a particular concern raised by the reviewer, and/or a presentation to the Council.

Comment was made that principal investigators can improve outcomes when they see the reviews. They can respond to the concerns that were raised.

In light of the findings around cultural diversity are the researchers anticipating utilizing or developing tools to address the cultural issues during the course of the study? Dr. Janvier attended as a public member and responded that she is developing a tool to address cultural issues.

Question was raised regarding process. Should the principal investigator be in the room when Council is discussing his/her grant? The Council meeting is open to the public; no public member can be excluded from attending the meeting. Comments from the public are reserved until the end of the Council meeting.

A concern was raised regarding the presentation of poster sessions while the work of the researcher is still in process – is it appropriate to share information at that point? There are several levels when one presents at conferences. During the early stages of the work the data is preliminary and frequently presented as a poster session. Poster presentations are not highly scrutinized. Poster sessions are enough to present to the public to comment on while considering them as preliminary. Platform presentations can also be preliminary and provide an opportunity for the audience to ask questions. The highest level is when a principal investigator is trying to get published in a journal and there are several levels within this level.

MOTION passed as presented with yes (8) and abstentions (2).

(3) Motion made by Dr. Sprott to approve year two funding (\$233,959) for grant number 10-401-SCH-E-0, PI- Gleb Shumyatsky, Ph.D., Rutgers, *Amygdala-enriched genes in behaviors related to ASD* and seconded by Ms. Reilly.

Discussion regarding significant problem since information presented by the principal investigator was limited. Motion was amended to ask preliminary and secondary reviewers to provide recommendations to Council on how this research can be strengthened to ensure that it's meeting the goals and objectives of the original research grant.

The reviewers will be asked to incorporate their recommendations into their reviews. The principal investigator will be asked for a corrective action plan which incorporates the suggested amendments and quarterly progress reports.

Note: Grantee will respond to Council's request and reviewers will be asked to comment on grantee's response.

MOTION with amendment passed with yes (8) and abstentions (2).

(4) Motion made by Dr. Meyer to approve year two funding (\$235,206) for grant number 10-406-SCH-E-0, PI- Bonnie Firestein, Ph.D., Rutgers, *Regulation of Synaptogenesis by cypin and neuroligin-1* and seconded by Dr. Sprott.

Discussion focused on the delays in progress as compared to the original timeline. Motion was amended to ask preliminary and secondary reviewers to provide recommendations to Council for corrective actions needed to ensure that the research will accomplish the goals and objectives of the original research grant. Also, further justification is needed as to how completion of this research will move the autism field of research forward.

Note: Grantee will respond to Council's request and reviewers will be asked to comment on grantee's response.

When considering to approve continuation funding or to amend a motion it must be noted that when these research grants were approved by Council in 2009 the principal investigators were only required to submit progress reports one month prior to the end of the first year. Council awarded two years of funding contingent upon submission of the progress report at the end of the first year. There was no requirement for approval of progress reports by the Council for continuation funding. We are now implementing a procedure that ensures accountability and one that should have been in effect when the grants were approved for funding for a 2 year period. Disapproval for the second year of funding can be challenged.

Note: Grantee will respond to Council's request and reviewers will be asked to comment on grantee's response.

MOTION with amendment was approved with yes (8) and abstentions (2).

(5) Motion made by Ms. Bell to approve year two funding (\$186,128) for grant number 10-409-SCH-E-0, PI- Gabriella D'Arcangelo, Ph.D., Rutgers, *Reelin abnormalities in Synaptogenesis and ASD* and seconded by Dr. Sprott.

Comment was made that based on the information provided it seems that this team has achieved the greatest amount toward their aims and publications with the least amount of resources in state funds requested.

MOTION passed as presented with yes (8) and abstentions (2).

NOTE: Dr. Barbie Zimmerman-Bier recused herself and left the room prior to presentation of the following grant:

(6) Motion made by Dr. Sprott to approve year two funding (\$259,529) for grant number 10-403-SCH-E-0, PI- Maggie Shiffrar Ph.D., Rutgers, *Perceptual-motor anticipation in individuals with Autism Spectrum Disorder* and seconded by Mr. Weitzen.

MOTION passed as presented with yes (8) and abstentions (1).

NOTE: Dr. Kendall Sprott recused himself and left the room prior to presentation of the following five grants and Dr. Zimmerman-Bier returned to the room.

(7) Motion made by Dr. Meyer to approve year two funding (\$234,775) for grant number 10-402-SCH-E-0, PI- Harvey Weiss, Ph.D., UMDNJ-RWJMS, *Autism and control of cerebral metabolism* and seconded by Ms. Bell.

Delays in research resulted from difficulty in obtaining rats required for the study. Motion amended to request revised plan and timeline from Principal Investigator. Does the Principal Investigator anticipate further delays?

MOTION passed with amendment yes (7) and abstentions (2).

(8) Motion made by Ms. Bell to approve year two funding (\$234,775) for grant number 10-404-SCH-E-0, PI- James Millonig, Ph.D., UMDNJ-RWJMS, *Genetic and Epigenetic Engrailed-2 ASD risk factors* and seconded by Dr. Meyer.

MOTION passed as presented with yes (7) and abstentions (2).

(9) Motion made by Dr. Evans to approve year two funding (\$238,190) for grant number 10-405-SCH-E-0, PI- Michael Lewis, M.D, UMDNJ-RWJMS, *Self representation and brain development in Autism* and seconded by Dr. Meyer.

Discussion concerning the first reviewers comments about data and late hiring of personnel. It was noted that the principal investigator can request a no cost extension that would enable him to continue the work beyond the second year. It was also noted that sometimes there is a delay in awarding funding resulting in a delay in hiring.

MOTION passed as presented with yes (7) and abstentions (2).

(10) Motion made by Dr. Evans to approve year two of funding (\$236,586) for grant number 10-407-SCH-E-0, PI- Emmanuel DiCicco-Bloom, M.D., UMDNJ-RWJMS, *En2 Regulates Forebrain Monoamines and behavior* and seconded by Ms. Bell.

Motion was amended with the recommendation that the principal investigator pay close attention to comments made by the second reviewer.

MOTION passed as amended with yes (7) and abstentions (2).

(11) Motion made by Dr. Evans to approve year two funding (\$235,038) for grant number 10-408-SCH-E-0, PI- Bharat Biswal, Ph.D, UMDNJ-NJMS, *Altered brain connectivity in Autism Spectrum Disorder patients* and seconded by Dr. Meyer.

MOTION passed as presented with yes (7) and abstentions (2).

VI. FY 12 Budget Presentation and FY 11 Report of Revenue and Expenditures

The format for the proposed 2012 budget was revised to compare the 2011 budget to the 2012 proposed budget (i.e. projections from 2011 as compared to proposed for 2012). Motion made by Ms. Bell to approve the 2012 budget and seconded by Dr. Evans.

Discussion concerned funding the collaborative database. Since the NJ Autism Center of Excellence RFA was not funded in FY 11 the funding is included in the FY 2012 budget. The amount includes further development of the database that will continue to be housed in the NJDHSS. Annual maintenance costs will be included in future budgets. Several line items were added to the FY 12 budget to cover expenses for grant reviewers and consultants. \$8,000 is budgeted for expenses for strategic planning. Funds can be moved around as necessary if additional funding is needed.

It was noted that not all expenses are in for FY 11 so the fund balance will be less once those expenses are deducted. The projected fund balance for FY 11 differs from the starting amount for 2012 since interest is deposited at the end of the fiscal year. A difference noted between the FY 11 and FY 12 budget is that the State appropriated operating expenses for FY 12. Operating expenses were funded from the trust account in FY 11 whereas state budget includes the expenses this year.

It was noted that funding for the second year of the basic science grants was included in the FY 11 budget and those funds were encumbered and are not included in the FY 12 budget. The \$8,750,000 is for new grants that will be awarded for the Autism Center of Excellence in FY 12 and will be encumbered for the five years of the grant. Starting in FY 13 (July 1, 2012-June 30, 2013) revenue will accumulate for funding basic science grants and other initiatives as determined by Council.

MOTION passed as presented with yes (10).

VII. Center for Neurological and Neurodevelopmental Health (CNNH) Presentation by Mark Mintz, MD, President and CEO and Q & A

Dr. Mintz provided an overview of CNNH's achievements with emphasis on the importance of Council funding in increasing and enhancing services throughout the three years (July 1, 2009-

June 30, 2011) of Council's funding for CNNH's Clinical Enhancement Center grant. Dr. Mintz's presentation was followed by a Q&A session. Dr. Eggerding, on behalf of the Council, thanked Dr. Mintz for a most informative presentation reflecting CNNH's accomplishments in enhancing services for individuals with autism.

VIII. Report of the Acting Executive Director, Martin T. Zanna, MD, MPH

Grant Monitoring – Site Visits and Quarterly Reports

As of June 30, 2011 all Clinical Enhancement Site visits have been completed. Dr. Zanna enjoyed meeting everyone and found the meetings to be very productive. Four Centers have been granted no cost extensions - Jersey Shore and Hackensack for 6 months and UMDNJ and Hunterdon for 12 months. Year 3 Summary reports are being reviewed and will be posted on Council's website. A total of 446 patients have been added to the Collaborative Database as compared to 241 patients reported at the June 20 Council meeting.

Website

Website postings since the last Council meeting includes the Council's Code of Ethics and the Office on Autism's publication entitled *Autism: Navigating Through the Maze: A Family Guide to Navigating the New Jersey Service Systems for Individuals with Autism Spectrum Disorders and other Developmental Disabilities*.

Autism New Jersey 29th Annual Conference – October 13-14, 2011

The basic science research and Clinical Enhancement Center Grantees were notified of the opportunity to participate in the poster session event on October 13 at Autism New Jersey's 29th Annual Conference in Atlantic City. Five research grantees and four Clinical Enhancement Center grantees have submitted applications – several with multiple abstracts totaling 16 posters. They are Dr. Randy Huron (Hackensack University Medical Center), Dr. Mark Mintz (Center for Neurological and Neurodevelopmental Health (CNNH)) – 2 posters submitted, Dr. Denise Aloisio (Jersey Shore University Medical Center), Dr. Audrey Mars (Hunterdon Medical Center), Dr. Gleb Shumyatsky (Rutgers), Dr. Walter Zahorodny (UMDNJ)—6 posters submitted, Drs. Yvette Janvier and Jill Harris (Children's Specialized Hospital)—2 posters submitted, Drs. Diccico-Bloom and Matthieu Genestine (UMDNJ) and Drs. Dennis Carmody & Michael Lewis (Rutgers). We also plan to display the Council's tabletop poster.

March 2012 Scientific Meeting of the Council funded Research Grantees

The Governor's Council is planning to host a scientific meeting in March 2012. This is a new initiative by the Council and the start of what we hope to ultimately be a statewide program to bring all autism researchers together annually for a summit to present and hear about the "State of Autism Research in New Jersey".

At the last meeting Dr. Zanna reported that seven basic science researchers funded by the Governor's Council expressed interest in participating. Since that time an additional five have been added with a total of twelve participating. A second mailing will be sent in September. In the meantime Madeleine Goldfarb and Linda Bocclair have been visiting hotels and planning the agenda along with a budget for the all-day meeting (date to be determined).

Rutgers University MOA Needs Assessment-Interim Report

The Phase 1 Interim Report will be sent to Council within a week. Dr. Dorothy Gaboda will attend the December Council meeting to discuss the Phase 1 Interim Report and progress on Phase 2. Phase 2 will be submitted in December and the final report in February 2012.

Scientific Advisory Committee (SAC)

Dr. Zanna made progress in recruiting members for the SAC. He has had contact with potential SAC members based on my review of the updated list of recommendations provided by Council. Rather than solicit everyone on the list, outreach was based on two factors: (1) Recommendations from Dr. Alice Kau who oversees the NIH funded Autism Centers of Excellence and (2) Previous priority rankings by Council members.

This resulted in four individuals with serious interest: Catharine Rice Ph.D., CDC (and affiliated with the Marcus Autism Center at Emory). Dr. Rice is part of the CDC's Autism Surveillance/monitoring Unit (ADDM); Ted Abel, Ph.D., Director of the Biological Basis of Behavior Program at the University of Pennsylvania; Stewart Mostofsky MD, Medical Director of the Center for Autism and Related Disorders at the Kennedy Krieger Institute; and Joseph Buxbaum Ph.D. Professor of Genetics and Genomic Sciences at The Mt. Sinai Medical Center. Two of the individuals (Drs. Rice and Abel) serve on national advisory boards. In addition, I've had several meetings with Dr. Kim Van Narden. She is a member of Dr. Rice's team at CDC and is currently embedded in our Family Health Services Department.

We need to ensure the SAC has the right balance of expertise in relation to the configuration of project requirements as specified on our RFAs. The list may be fine-tuned with Council's help as we go along. Since the Statute requires that the SAC be composed of 2 clinicians and 3 researchers we'll probably need to recruit another clinician.

Interagency Task Force on Autism

Dr. Zanna attended my first meeting of this group in August. Representative from the Department of Education and the Department of Human services, along with Ms. Bridget Kelly (First Lady Mary Pat Christie's representative) and Eric Synder (Constituency Liaison, Office of the Governor) were present.

The focus was on professional education with several organizations reporting on activities statewide. Dr. Zanna summarized the autism training and education presented by the Clinical Enhancement Centers to healthcare professionals and the community in general. Subsequently

we requested more detailed information from the Clinical Enhancement Centers per request of Jonathan Sabin who is staff to the new task force. Additionally, Dr. Susan Evans supplied information on what professional training related initiatives are being conducted by Special Health Services within the Division of Special Family Health Services.

Council asked if the meetings are open to the public and if minutes of the meetings are posted. Dr. Zanna will ask Jonathan Sabin. It was suggested that we should link the Office on Autism's website to the Council's website. Note: The Council's website does include a link under "Publications" to the Office on Autism's resource document. Accessing the document leads the viewer to the Office on Autism's website.

IX. Comments by public member attendees

Dr. Audrey Mars asked if information is available regarding the timeframe for submission of applications for the Autism Center of Excellence RFA. The plan is to submit the RFA to the NJ Register in November for publication in early December. Grants will be awarded in FY 12 with the understanding that sufficient time will be allocated for applicants to plan, form collaborations and write their proposals.

X. Closed session

Ms. Kirchner described the purpose and process for the closed session, referring to the Open Public Meeting Act b5, NJ Statute 10:4-12. Going into a closed session is necessary because the information to be discussed with the Council involves the Request for Application (RFA) and opening to the public could adversely affect the public interest if discussion of the specifics were disclosed publically prior to the RFA public release.

Ms. Kirchner requested that any council member with a potential for conflict recuse themselves and leave the meeting. The public attendees and the following Council members left the meeting: Drs. Eggerding, Sprott and Zimmerman-Bier.

Daphne Robinson, Ph.D., President, Strategic Consulting, presented a preview of the NJ Autism Center of Excellence RFAs with the following Council members present: Drs. Meyers and Evans, Ms. Morvay, Ms. Reilly, Mr. Weitzen and Mr. Cortland (via phone). Note that Dr. Meyer left the presentation after 10 minutes due to a previous commitment. Each member present signed a confidentiality form.

XII. Adjournment

MOTION by Dr. Evans to adjourn the meeting and seconded by Mr. Weitzen.

MOTION passed with all in favor. The meeting was adjourned at 9:20 PM.